

ON FORMING AN INSTITUTIONAL ETHICS COMMITTEE: THE DILEMMAS' DILEMMA

J. DAVID SEAY, ESQ.

Vice President and Counsel
United Hospital Fund of New York

Adjunct Professor of Law
Benjamin N. Cardozo School of Law,
Yeshiva University

New York, New York

SINCE the 1976 case of Karen Ann Quinlan,¹ which brought widespread attention to policies and procedures surrounding ethical issues in medicine, hospitals and physicians increasingly have focused attention on what have come to be known as institutional ethics committees. The public controversy surrounding the Baby Doe case in Indiana,² the Baby Jane Doe case in New York³ and the federal government's various attempts, recently culminating in model infant care review committee regulations,⁴ to involve itself in medical ethical decision making, all dramatically focus attention on particularly vexing problems which call for change, or at least some steps forward, in the way in which medical ethical decisions are made. Similarly, the prosecution of two California physicians on first degree murder charges⁵ for termination, at the family's request, of intravenous feeding therapy from a seriously brain damaged and comatose patient raises not only the medical and ethical issues, but also brings into play the interrelationship of these private issues with public policy, namely, the various criminal statutes.

Recent advances in medical technology and therapies have enabled us to prolong or to sustain human life well beyond what could have been imagined only a few short years ago. Some observers of this phenomenon have voiced concern that we have not made concomitant advances in our ability to make appropriate decisions. Our achievements on the ethical or human side of this equation have lagged behind our scientific accomplishments, and have stimulated a serious reexamination of the basic health professional-patient rela-

Address for reprint requests: United Hospital Fund of New York, 55 Fifth Avenue, New York, N.Y. 10003

tionship. The issues raised include: informed consent, treatment of severely deformed or handicapped neonates, do not resuscitate orders, refusal of lifesaving treatments, biomedical research and human experimentation, proxy consent for children and incompetent adults, and genetic screening and engineering.

The basic human dilemma of biomedical ethics is complicated still further by the problem solvers themselves. The diverse perspectives and professions of individuals involved, including not only medicine but also law, social work, nursing, religion and the family's own perspectives, underline the scope and depth of the challenges. The many approaches to solving the dilemma created by all of this can be summarized, at the risk of oversimplification, as ranging from the view that such matters are wholly medical decisions to the view that medicine plays merely a technical and tangential role in this highly value laden process.

The movement toward institutional ethics committees, while still quite formative, represents the development of a process to address these issues rather than a precise solution or ethical theory. Individual committees' roles and determinations will vary and may reflect specific schools of thought. But, despite the inevitable confluence of mixed opinion, a process for sorting through these intricate and highly complex topics is an important first step and, indeed, may well yield significant benefits to patient care and to those concerned with the ethical issues that it often raises.

It is quite fitting, therefore, that hospitals, physicians, and others involved in health care begin to question what institutional ethics committees are, and to examine whether they can provide an appropriate mechanism for use within a particular hospital or other health care institution. This paper undertakes to assist this process by raising issues, attempting to explain what an institutional ethics committee is and elucidating what kinds of benefits it may and may not provide. The paper also suggests careful scrutiny of the underlying motivations behind formation of such committees in an effort to see if those motivations match the potential benefits which may be derived. In addition, a brief survey of some of the policy positions of selected national and state hospital and medical organizations is provided, as well as an assessment, to the extent possible, of some of the legal implications of institutional ethics committees. A series of recommendations are presented in an effort to guide a health care institution in determining whether it should form an institutional ethics committee, and, if so, what its structure and mandate should be.

FUNCTIONS AND RESPONSIBILITIES

There is no absolutely clear consensus as to what an institutional ethics committee is, what its mandate should be or how it should be structured. However, one can look to trends in their formation around the country and to policy statements issued by various organizations to build a rough composite of what may emerge as an accepted approach.

It is of paramount importance that the sphere of activity of an institutional ethics committee be clearly delineated at all times. This is not to say that the full potential range of a committee's activities need be instituted at its inception. It does mean, though, that all parties must clearly know at any given time what the functions of the committee are and what they are not. This clarity also serves to allay the fears of some physicians and others who may be reluctant to participate, to ease the administration of the committee and to help to cope with, if not to resolve, some of the inevitable territorial or "turf" problems within the institution.

The range of functions of such a committee may be broad in their application, yet are startlingly simple when generically described. The three major functional areas of the institutional ethics committee are: education, policy and guideline development and consultation.⁶

Education. The committee's role in education logically precedes the others. Rarely in a group as large and diverse as most ethics committees will there be found equality in levels of expertise regarding ethical issues. Therefore, it is quite appropriate and, in fact, requisite that the first charge to such a committee be to engage in an intense program of self-education in medical ethical issues. Later this function can be enlarged to provide ongoing continuing education to physicians and others within the institution.

There are various ways by which a committee can begin to undertake this exercise, including review of the literature,⁷ discussions with one another on the committee and a more systematically designed curriculum featuring visiting lecturers expert in the problems to be explored. Hospitals in the New York City area are particularly well placed in this regard in that there are a number of nationally prominent scholars and practitioners familiar with these topics and available to speak to the committee. Because a number of types of ethical issues daily confront health professionals in institutional settings and, because the representation on most ethical committees is broad, it is recommended that the scope of the committee's educational activities not be limited, but rather should extend to the full range of concern within the institution.

Policy and guideline development. It has been suggested, however, that education of this sort might be difficult to achieve in a vacuum and therefore that the committee might best begin this function with a concrete objective. The most logical activity to stimulate and focus these activities could be development of institutional policies regarding such issues as human subject protection in biomedical experimentation (such activities already exist in most hospitals), "code blue" guidelines, do not resuscitate guidelines, treatment of severely handicapped newborns, treatment of patients having suffered irreversible neurological damage or deterioration who are maintained on life support systems and problems involving geriatric medicine and informed consent. When faced all at once, these issues can be overwhelming. Therefore, it is practically suggested that the initial mandate be limited to one or two areas within the first six months or year.

These first two functions, education and development of institutional guidelines and policies regarding ethical problems, may very well be as far as an institution may want its committee to go, at least in the beginning. Again from a practical point of view, it might be advisable, initially, to charge the committee with education and policy making and with the task of making recommendations to the hospital's board of trustees as to which additional functions it may wish to pursue.

The legal implications of an institution having prescribed policies or guidelines in some of these areas are still murky, especially in the state of New York, and make it difficult to say unequivocally that guidelines are advisable. However, the interest of medicine and patient care may well be served by a system that provides a more consistent and coherent means of addressing similar problems over time, and which encourages a multiplicity of perspectives in the process. These very reasons alone may well justify an institution to move in this direction.

Some of the issues with which the committee must struggle, and for which unfortunately there are no clearcut answers, include who makes the decision and how the decision is made to terminate life support systems for a patient, the extent to which these decisions and guidelines upon which they were based are included in the patient's medical record, the state's criminal code and its interpretation with respect to homicide and suicide statutes and protection of confidentiality of the patient and the patient's records. The formidability of these determinations, however, has not deterred many institutions around the country from moving ahead with great satisfaction in these areas. Indeed, it could be argued that not to address these issues at all would create a far worse situation.

Consultation. The last of the most common functions of institutional ethics committees is consultation in individual cases. This is a very delicate area and one which causes concern to many, but need not do so. The issue which gives rise to this false controversy revolves around whether or not the committee itself has decision-making authority. Some professionals may be fearful of a tribunal empowered with decision-making authority which could usurp the traditional care giving and decision making roles. Most problems associated with this issue can be avoided by making it clear from the outset that the committee has no authority other than consultative or advisory. In fact, the American Hospital Association guidelines for hospital committees on biomedical ethics suggest that "ethics committees should not serve as professional review boards, as substitutes for legal or judicial review, or as 'decision-makers' in biomedical ethical dilemmas. An ethics committee should not replace the traditional loci of decision making on these issues."⁸ The function of consultation and case review can be met by simply having the committee, or some subcommittees of its members, available to serve as a sounding board or additional opinion giver in difficult situations to parties who may seek it. The traditional decision makers, that is to say, the physician and family, would thereby still make decisions regarding patient care but would be able to do so with additional assistance and with the satisfaction that they have not done so alone. This sort of "support system" for patients, family, and health care givers is an important aspect of the institutional ethics committee that should not be overlooked.⁹ In fact, it may constitute the very essence of not only the roles which insitutional ethics committees can play, but also the traditional method of medical decision making, enhanced or improved upon in this expanded and positive way.

A permutation of this process, and one which may be advisable for larger multiservice institutions, would be for the committee to divide itself into subcommittees either along specialty lines, such as subcommittees for neonatology, geriatrics, cardiology and the like, or along the lines of ethical decision making function such as research, withholding treatment, nutrition, informed consent etc. Each subcommittee could serve as consultant as required in the individual areas, and the full committee could then serve as an appeals mechanism, providing additional input to the subcommittee's consultation. The full committee would, of course, still perform its general functions of education, policymaking and guideline development. This would allow great diversity of input and expertise on the committee as a whole, while at the same time providing a more functional and less cumbersome mechanism for addressing individual practitioners, patients and families. It would

also further the goal expressed by some observers of postponing the point at which the law intervenes by offering several "nonlegal" steps before relying upon the courts as a last resort.

COMPOSITION

As important as function is the membership of institutional ethics committees. Here, although the exact representation and numbers of representatives may vary from institution to institution, there is some degree of consensus about some of the larger issues. Specifically, these committees are not physicians' committees nor are they committees of the hospital administration. By necessity, though, they must exist within the institutional structure of the institution, reporting ultimately to the board of trustees. Furthermore, and of initial concern to some, these committees are not limited solely to traditional medical care givers. In a word, institutional ethics committees are multidisciplinary.

Represented on such committees are usually physicians, nurses, social workers, a patient or family representative, administration, clergy, trustees, philosophers or others trained in ethics, attorneys and lay or community representatives. Although the majority of members on the committee may well represent traditional medical care givers, inclusion of others is crucial to provide a broader mechanism for review and input and to help dispel misconceptions and allay fears within families or the community about the way in which modern institutional health care decisions are made. This latter point should be of obvious value to both institution, patient and family. To do anything other than move in the direction of diversity in this area would be either to do nothing, and proceed to make medical ethical decisions in the same manner as in the past, a position that has proved untenable in many hospitals, or to revert further toward the closed process whereby medical decisions are made solely by the physician, a trend which would appear not to be viable.

The American Hospital Association guidelines state that "to be most useful and effective, an ethics committee should be a standing committee, and its members should be approved by the appropriate authority within the institution. This structure provides continuity and enhances the credibility of the committee."¹⁰ These guidelines go on to say that "the committee should meet regularly and whenever necessary to provide advice and recommendations. As a general rule, no one who is personally involved in the case in question should serve on the committee while the case is being consid-

ered.”¹¹ The guidelines also suggest that the committee’s purview should be limited to issues that relate to patient care, that any person involved in the patient’s treatment may rightly bring a question before the ethics committee,¹² and such request may be anonymous if desired. However, with the committee’s function clearly defined as consulting and advisory to decisions ultimately reached by the physician and family, there should be little cause for legitimate concern about potential misuse of the system. Indeed, the formation of the institutional ethics committees would appear to be a growing phenomenon around the country, and estimates of the percentage of hospitals having such committees range from 16.4%¹³ to 55%,¹⁴ depending on the survey taken, where it was taken and what definition of institutional ethics committee was used. That the number of committees is increasing may indicate a growing level of satisfaction with their operation and outcome.

LEGAL CONCERNS

It is clear that institutional ethics committees and the problems they are designed to address present distinct challenges to all involved in modern health care. A number of organizations have supported institutional ethics committees as one approach to these problems that should be seriously explored. The President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research supported such committees,¹⁵ as has the American Academy of Pediatrics,¹⁶ American Society of Law and Medicine,¹⁷ American Hospital Association¹⁸ and the American Medical Association.¹⁹ In New York State Governor Cuomo has formed a special commission to examine human and ethical issues specifically involving medical technology,²⁰ and the State Department of Health is encouraging development of Do Not Resuscitate guidelines for use statewide. The multitude of organizations supporting such committees may be inconclusive substantively or legally, but at least there may be some comfort in numbers.

The numbers, however, provide little more than comfort when legal issues fall close to home and the case in question is one’s own. As may be anticipated in a society grown litigious in all aspects of life, including medicine, these types of difficult treatment decisions are frequently posed in a legal context, with concerns of liability or potential liability, protection of rights and interests and “risk management” raised by various parties. This paper does not attempt to provide legal advice or even a thorough analysis of all possible hypothetical situations. However, a simple analytic frame-

work follows whereby a number of the significant legal issues are at least raised for consideration.

Most of the issues of legal significance would seem to fall into three categories: issues that relate to defending the rights of the patient, issues that relate to protecting the interests of the provider or providers and issues that relate to preserving the role of the state, that is to say, society's interests. Ideally, these issues should all be consonant with each other, but as McCormick²¹ and Pellegrino²² have noted, determining just what is in the "patient's best interest" is not always a simple task. Some of the more prominent issues that relate to a patient's rights include: informed consent, substituted consents for infants and incompetent adults, confidentiality of the patient and the medical record and the rights to request or refuse treatment.

Issues that relate to protection of the providers include the duty of care owed to the patient, the alleged breach of which leads to malpractice actions; the theory of agency, whereby certain acts of employees or others acting on behalf of an institution are "imputed" to the institution; the so-called risk management activities which seek to lessen an institution's vulnerability to liability; and the various requirements of law, such as Institutional Review Boards, Professional Review Organizations and the recommended Infant Care Review Committees. Issues that relate to the public good are, as have been mentioned, criminal statutes concerning homicide, suicide, assault and battery and the like.

Multidisciplinary institutional ethics committee can play a positive role in these issues. "In the ideal decision, these components are congruent. . . . Whatever the case, the clinical decision must attend to all of the components. It is thus clear that best interests is a broad human judgment, not a narrowly scientific one. And once that is understood, it becomes clear that competences other than medical competence *can* shed light on the clinical decision."²³

It is relatively safe to say, however, that if the *sole* motivation for creation of institutional ethics committees is to bolster an institution's or an individual physician's position in any potential medical malpractice action, that is, to lessen potential malpractice vulnerability, then the creation of the committee should not be undertaken. At least as of this date, standards for deciding negligence in a medical malpractice action have not changed so as to substitute a committee's standard for the community's, and it may be some time before the institutional ethics committee will have an impact in this area. Indeed, it has been suggested that the existence of such committees may actually harm the physician or institution in cases where the treatment or ther-

apy pursued was at odds with a committee opinion, the outcome is unfavorable, and the treatment is contested in court. Although this situation could be hypothetically possible, it would appear not to have occurred to a significant degree. In fact, this negative potential may very well be counterbalanced by the benefits attendant upon use of an ethics committee.

In the long run, the institution's interests may best be served by developing and implementing the best possible mechanism—one designed to evolve with technological and other environmental changes—to assure promotion of the "patient's best interest" in a clear, consistent, and intelligent manner. These committees may help to achieve that goal.

What follows then, are a few recommendations which, although admittedly circumspect, may be helpful for an institution considering formation, or at least study of, an institutional ethics committee.

RECOMMENDATIONS

Move cautiously. Whatever is done should be done slowly and with caution. The areas within which an institutional ethics committee proceeds are still very unclear, so it is best not to move quickly when it is not certain which way to move. Education, study and an open process may prove to be valuable tools in this effort.

But move. From a practical point of view, already stated, the institution would best be advised to decide to form such a committee, to decide upon its composition and members and then to charge it initially with educational functions and with developing some clearly defined set or sets of operational guidelines. Additionally, the committee would be charged with reporting back to the hospital board of trustees or other identified hierarchy with specific recommendations as to its long-term functions and responsibilities. Even with this cautious approach, there is still plenty for the committee to do.

Be multidisciplinary. Any institutional ethics committee, or precursor body, should be multidisciplinary in its composition. Other configurations may be appropriate for a variety of other reasons, political or otherwise, but it simply would not be an institutional ethics committee as currently viewed, nor could it achieve its goals. Deciding just what representative positions ought to be on the committee and who ought to occupy them may well be a thorny task, but one that cannot be ignored. Since the committee should have the full benefit of institutional auspices and sanction, such committees should be formed within the hospital's structural hierarchy, reporting ultimately to the board of trustees. Administrative and medical representatives are essential to such

a committee but probably should not form in either case a majority. One approach that may promote ease in this process is to form a special study group or precursor body to assist in the design of the committee. Although this group may be somewhat smaller than the eventual committee itself, it too must be multidisciplinary and might best include those individuals within the institution having particular interest or expertise in medical ethics.

Make it official. Whatever committee is eventually formed, it should have the benefit of institutional auspices and authority. This simply means that the committee is not an *ad hoc* or informal body acting on its own, but rather is an official, and perhaps even standing, committee of the hospital with full authority to act in the areas with which it is charged.

Clearly define committee membership. The institutional ethics committee should have specific and clearly identified members with tenures of some significant length. It must always be clear who is a member of the committee and who is not, and operating procedures should specify such issues as abstinence from participation in decisions in which a participant is involved, protection of patient confidentiality and rotation within the committee. Rotation is a healthy phenomenon, but it would be wise to provide tenures of the length of at least a year to give members ample opportunity to become familiar with the subject matter. Staggered terms likewise would be beneficial.

Give a clear and concise mandate. The committee should first be charged with its own education, a process which might best be undertaken, as mentioned, by charging it also and simultaneously with the task of developing some set or sets of recommended institutional policy or guidelines. This could be a uniform Do Not Resuscitate policy, infant care guidelines or other similar needs of the institution.

Limit the charge to recommendations. The committee, or precursor study group, should present the fruits of its deliberations to the institution in the form of nonbinding recommendations, which would then be reviewed by administration with advice of counsel, and channeled through appropriate bodies before ultimate presentation to the board of trustees. These initial recommendations may be simply the form, structure and suggested responsibilities of the committee.

Avoid provincialism. Do not shrink from the duty to find out what neighbor institutions in the same city and region are doing in this area. This will not only help in evaluating the specific recommendations, but also may assist in moving toward consensus in medical ethical decision making.

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